

Women With Disabilities Australia (WWDA)

## **WWDA Autism Research Project**

The experiences of Autistic women and girls

June 2023



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Women With Disabilities Australia (WWDA) has Special Consultative Status with the Economic and Social Council of the United Nations.

#### Awards

Winner National Human Rights Award 2001

Winner National Violence Prevention Award 1999

Winner Tasmanian Women's Safety Award 2008

#### Nominee

UNESCO Prize for Digital Empowerment of Persons with Disabilities 2021

Nominee National Disability Awards 2017

#### Nominee

French Republic's Human Rights Prize 2003

Nominee UN Millennium Peace Prize for Women 2000

Certificate of Merit Australian Crime & Violence Prevention Awards 2008

#### Finalist

International Zero23 Award, Information and Communication Technologies (ICT)



Women With Disabilities Australia (WWDA)

# About Women With Disabilities Australia (WWDA)

Women With Disabilities Australia (WWDA) Inc is the national Disabled People's Organisation (DPO) and National Women's Alliance (NWA) for women, girls, feminine identifying, and non-binary people with disability in Australia. As a DPO and an NWA, WWDA is governed, run, and staffed by and for women, girls, feminine identifying and non-binary people with disability.

# WWDA uses the term 'women and girls with disability', on the understanding that this term is inclusive and supportive of, women and girls with disability along with feminine identifying and non-binary people with disability in Australia.

WWDA represents more than 2 million women and girls with disability in Australia, has affiliate organisations and networks of women with disability in most States and Territories, and is recognised nationally and internationally for our leadership in advancing the rights and freedoms of all women and girls with disability. Our organisation operates as a transnational human rights organisation - meaning that our work, and the impact of our work, extends much further than Australia. WWDA's work is grounded in a human-rights based framework which links gender and disability issues to a full range of civil, political, economic, social, and cultural rights. All WWDA's work is based on co-design with and participation of our members. WWDA projects are all designed, governed, and implemented by women and girls with disability.

Disabled People's Organisations (DPOs), also referred to as Organisations of Persons with Disabilities (OPDs) are recognised around the world, and in international human rights law, as self-determining organisations led by, controlled by, and constituted of, people with disability. DPOs/OPDs are organisations of people with disability, as opposed to organisations which may represent people with disability. The United Nations Committee on the Rights of Persons with Disabilities has clarified that States should give priority to the views of DPOs/OPDs when addressing issues related to people with disability. The Committee has further clarified that States should prioritise resources to organisations of people with disability that focus primarily on advocacy for disability rights and, adopt an enabling policy framework favourable to their establishment and sustained operation.<sup>1</sup>

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### **BACKGROUND AND INTRODUCTION**



### **1. BACKGROUND**

- 1.1 In May 2023, the Department of Social Services invited Women with Disabilities Australia (**WWDA**) to prepare a report on the issues impacting individuals who experience barriers to assessment, diagnosis, supports and services for Autism Spectrum Disorder (**Report**). This Report will inform the Australian Federal Government's National Autism Strategy. In particular, the Department of Social Services requested that WWDA consider the unique experiences of Autistic women and girls.
- 1.2 WWDA welcomes the opportunity to provide this Report. In developing this Report, WWDA consulted with Autistic women, girls, and non-binary people whose voices inform our Report (**Participants**).

## **2. INTRODUCTION**

- 2.1 In recent years, it has become widely recognised that research-based understandings of Autism Spectrum Disorder (hereafter referred to as Autism) have been male-dominated and euro-centric.<sup>2</sup> Emerging research indicates that current diagnostic processes are an inaccurate means of identifying the diagnoses and support needs of other Autistic populations.<sup>3</sup> This includes Autistic women and girls, and Autistic people in other marginalised communities, such as those who are Aboriginal and Torres Strait Islander, Culturally and Linguistically diverse, and lesbian, gay, bisexual, transgender, queer, intersex, asexual, and gender diverse (**LGBTQIA+**). Autistic people also show greater diversity in gender and sexual identity than seen in the general population, but researchers rarely seek to include sex and gender-diverse individuals in their studies.<sup>4</sup>
- 2.2 It is now broadly accepted that women and girls face unique barriers to the identification of, and support for, an Autism diagnosis. Emerging research also recognises that Autistic women and girls, and gender diverse people, may present differently to their male counterparts.<sup>5</sup> This difference in presentation may lead to misdiagnosis or under-diagnosis of Autism, where it inconsistent with the diagnostic criteria based on the traits of Autistic males.
- 2.3 As the majority of Autism research is conducted overseas, this research paper aims to contribute to a body of literature elevating the voices of Australian Autistic individuals, while reflecting the valuable evidence-based research conducted nationally and internationally.<sup>6</sup>

## **AUTISTIC WOMEN AND GIRLS**



## **3. AUTISTIC WOMEN AND GIRLS**

### Prevalence

- 3.1 An estimated 80% of Autistic women and girls remain undiagnosed at the age of eighteen.<sup>7</sup> Misconceptions about the prevalence of Autism in women and girls continue to impact access to diagnostic and support services. Historically, Autism was believed to be a predominantly male diagnosis. Early research tended to exclude women and girls from study populations entirely, and studies examining the validity of diagnostic tools continue to use primarily male samples.<sup>8</sup>
- 3.2 Autism research is impacted by, and in turn impacts, this diagnostic gender bias. When research is conducted, male-normed diagnostic tools are often used to confirm a diagnosis of Autism and exclude study participants who do not meet the requisite cut-offs, even where a diagnosis has previously been made by a clinician.<sup>9</sup> In effect, unless actively remedied, gender-biased research perpetuates gender-biased research.
- 3.3 Emerging research indicates that Autism is far more prevalent in women and girls than previously estimated. While there remains a significant diagnostic gap, recent studies indicate that the true male-to-female Autism ratio is inflated by deficiencies in diagnostic processes.<sup>10</sup>
- 3.4 Assessments of the sex ratio in the Autistic population vary significantly, with studies finding ratios ranging from 5:1 to 1:1.<sup>11</sup> The most comprehensive review of the gender and sex ratio analysed fifty-four studies with 13,784,284 participants.<sup>12</sup> Overall, the review identified a pooled male-to-female odds ratio of four males to every one female. However, the review found significant variation between studies. Studies that involved identifying Autistic children based on whether they had a pre-existing diagnosis found a ratio of approximately 4.6:1 (four males to one female). The studies that involved undertaking diagnostic assessments to identify Autistic children found a ratio of 3.25:1 (three males to one female).<sup>13</sup> The results of this review highlight a diagnostic gender bias and indicate that Autism is significantly more common in women and girls than previously estimated. Misconceptions about its prevalence in women and girls must be remedied by comprehensive screening.
- 3.5 The gender ratio demonstrated amongst Autistic adults is also lower (2:1) than in child services (5:1).<sup>14</sup> This disparity, together with a significant difference in the average age of referral and diagnosis for girls compared to boys, indicates a delayed recognition of Autism in women and girls.<sup>15</sup>
- 3.6 In order for girls to receive a diagnosis, they require a greater "symptom" threshold:<sup>16</sup> girls who meet criteria for Autism on diagnostic measures may be more significantly affected in real-world settings than Autistic boys.<sup>17</sup> Where girls do meet the diagnostic criteria for Autism, they are more likely to present with intellectual

disability and behaviours reported as challenging.<sup>18</sup> In the absence of such factors, girls are less likely than boys to meet diagnostic criteria at equivalently high levels of Autistic traits.<sup>19</sup>

# Experiences of Autistic women, girls and non-binary people

3.7 In recent years, the United Nations has drawn attention to the marginalisation of Autistic people, holding an annual event to promote Autism awareness and understanding. Similarly, the World Health Organisation has acknowledged:

...autistic people are often subject to stigma and discrimination, including unjust deprivation of health care, education and opportunities to engage and participate in their communities.

...People with autism require accessible health services for general health-care needs like the rest of the population, including promotive and preventive services and treatment of acute and chronic illness. Nevertheless, autistic people have higher rates of unmet health-care needs compared with the general population. They are also more vulnerable during humanitarian emergencies. A common barrier is created by health-care providers' inadequate knowledge and understanding of autism.<sup>20</sup>

- 3.8 In an Australian context, Autistic people are at increased risk of violation of a broad range of basic rights, including those under the Convention on the Rights of Persons with Disabilities.<sup>21</sup>These include:
  - (a) Healthcare: Autistic adults in Australia experience more barriers to healthcare than their non-Autistic counterparts.<sup>22</sup>
  - (b) Education: Autistic students have the worst educational outcomes of any students with disability in Australia.<sup>23</sup> Autistic students may be denied enrolment, subject to partial enrolment, or otherwise treated unfairly.<sup>24</sup>
  - (c) Work and employment: Autistic people in Australia experience high rates of unemployment or under-employment. Recent data indicates that many Autistic Australians lack the support available to find a job, experience poor health as a barrier to employment, and report that potential employers do not understand Autism.<sup>25</sup>
  - (d) Access to justice: Autistic people are overrepresented in the criminal justice system and experience a lack of understanding and support across services.<sup>26</sup> Risk of interaction with the justice system may be increased by late or missed diagnosis, housing insecurity, insufficient resources and poor educational experiences.<sup>27</sup> Further, some Autistic characteristics may be misinterpreted by law enforcement, increasing the likelihood of arrest, detainment, seclusion or restraint.<sup>28</sup>

- (e) Freedom from exploitation, violence and abuse: It is well established that violence against women and girls with disability is far more extensive, frequent and diverse in nature than violence amongst either their male counterparts or women without disability.<sup>29</sup> Several studies have indicated that Autism is an additional factor in a person's vulnerability to gender-based violence, finding that Autistic women, girls and gender diverse people may be two to three times more likely to experience sexual harm than non-Autistic women.<sup>30</sup>
- 3.9 For women, girls and non-binary people with disability, gender inequality, disability inequality and discrimination are interconnected and inseparable. We experience the compounding effects of disability discrimination and gender-based discrimination at the intersection of both identities. This means that all forms of intersecting inequality and discrimination must be recognised and dismantled for Autistic women, girls and non-binary people to enjoy full social, economic and political participation. Intersectionality is a key element of the human rights approach to disability required by the Convention on the Rights of People with Disabilities (CRPD).<sup>31</sup>
- 3.10 For Autistic women, girls and non-binary people in particular, gender is also a barrier to adequate support due to widespread gender biases in Autism research, screening and services.

## GENDER BIAS IN THE DIAGNOSTIC PROCESS



## 4. GENDER BIAS IN THE DIAGNOSTIC PROCESS

### **Referral and access to diagnosis**

4.1 Misconceptions about the prevalence of Autism in women and girls continue to pose a barrier to diagnosis, beginning with referral. One contributing factor is that key professionals (including educators, family doctors, paediatricians, psychiatrists, and psychologists) are not equipped with adequate knowledge about Autism, and are less likely to identify Autistic traits in women and girls due to a belief that Autism is primarily a male diagnosis.<sup>32</sup> Gender-based biases appear to be particularly common amongst professionals who do not specialise in assessing neurodevelopmental conditions, but who "are nevertheless influential gate-keepers" to relevant services, such as educators.<sup>33</sup> One Participant recalled:

I had a really challenging time even finding a GP to write the referral for me to get started. Then when I found the first doctor to do it, at the first appointment he told me I couldn't possibly have autism because I was able to hold a conversation well with him. Never mind the fact I was masking as though my life depended on it! Luckily I was able to find a doctor who was willing to listen, but that took a great deal of time, money and stamina and I don't know if I could go through that again, ever.<sup>34</sup>

- 4.2 Caregiver perception and concern also play a crucial role in referral for Autism assessment. Autistic women and girls without intellectual disability are more likely to demonstrate developmentally appropriate language skills than Autistic males.<sup>35</sup> As language delays are generally the first reported concern among parents of Autistic children,<sup>36</sup> this difference may contribute to lower rates of referral for diagnosis. Further, caregivers may seek to draw professional attention to a child's development where the child's behaviour is considered challenging. This may be due, in part, to the common mischaracterisation of Autism as a "behavioural disorder", an interpretation arising from the medicalised and deficit-based diagnostic criteria.<sup>37</sup> This mischaracterisation poses an additional barrier to diagnosis for women and girls, who are more likely to internalise, rather than externalise, their Autistic traits.
- 4.3 Importantly, caregiver perception is also not without the influence of social norms and expectations, and there is evidence to suggest that caregiver perception of behaviour "severity" may be influenced by a child's gender.<sup>38</sup> For example, internalising or withdrawal behaviours in girls, such as shyness or anxiety, may be less likely to cause concern because compliance is a trait typically attributed to and expected of girls.<sup>39</sup> Behaviour that violates gender norms may be more likely to cause interpersonal challenges, and thus raise concern among caregivers or educators.<sup>40</sup>

#### One Participant described:

The idea that school reports need to be referred to in diagnosis feels odd, because clinicians are looking for "concerns" that teachers raised. All of my reports read that I was "a pleasure to have in class". I was the ideal pupil because I'm Autistic, not in spite of it. Teachers wouldn't see my constant anxiety, my feeling of isolation, or the meltdowns I had at home. They just saw a smart, shy kid who wanted to follow all of the rules.<sup>41</sup>

- 4.4 Autistic traits and behaviours are less likely to be labelled "Autism" unless they are experienced negatively or are said to cause impairment, consistent with the deficit-based diagnostic model.<sup>42</sup>
- 4.5 Participants who had sought out referral and diagnosis themselves, also reflected on the costs of assessment, and concern that gender bias could result in no diagnosis despite significant financial loss.

I paid around \$1500 out of pocket for an assessment via Telehealth, and that was a lot more affordable than assessment services in my area. I was so worried that I'd end up with a clinician who didn't understand Autism in women and girls, and spend all of that time, emotional energy, and money for nothing.<sup>43</sup>

#### Another Participant explained:

I was really lucky my parents helped me and I saved up. But imagine if that hadn't happened. I probably still wouldn't have a diagnosis. I'd probably still be struggling to figure out who the hell I was. What the hell was bloody wrong with me? Now I know nothing's wrong with me, I know that now, but I didn't know that before.<sup>44</sup>

### **Diagnostic criteria**

- 4.6 There is a disproportionate number of women and girls who score highly on measures of Autistic traits, but do not meet the current diagnostic criteria for Autism.<sup>45</sup> This suggests a gender bias inherent in the diagnostic criteria and/or the tools by which an individual is assessed.
- 4.7 Autism is medically defined as a heterogenous neurodevelopmental disorder, characterised by "deficits" in social communication and interaction, and the presence of restricted and repetitive behaviours.<sup>46</sup> Diagnosis is categorical, and obtained "when a clinician determines that a threshold of relatively abstract features which make up autism criteria... has been reached".<sup>47</sup>
- 4.8 The diagnostic criteria for Autism Spectrum Disorder, as set out in the Diagnostic and Statistical Manual (**DSM-5-TR**) requires that individuals have persistent deficits

in each of three specified areas of social communication and interaction, and at least two of four types of restricted, repetitive behaviours.<sup>48</sup> Studies indicate that women and girls can present differently to males in relation to this core criteria.<sup>49</sup> As one Participant told WWDA:

It's no wonder so many women are never getting a diagnosis or not getting a diagnosis until their later life. Or how many people we know that accidentally got a diagnosis because they happened to run into someone at the right time...The diagnostic criteria, they need to fix it. It doesn't work. It doesn't show what we experience. I think it's a miracle any of us actually get the diagnosis. But what really worries me is how many people are not getting the diagnosis?<sup>50</sup>

4.9 Clinical diagnosis of Autism also relies on observations and reports, neither of which may be separated out from the social structures in which gender norms operate. As Parish-Morris, et al. (2017) have written:

ASD experts make diagnostic decisions based on observable behaviour, and subtle differences in how a child moves or talks will influence the way they are perceived. Gender socialization or social mimicry may lead to "camouflaged" behaviour in girls with ASD, which, combined with widely held gender biases about how girls and boys should behave and true biological sex differences, likely complicate efforts to effectively identify and treat boys and girls with ASD.

Recent attempts to reduce bias by directly sampling behaviour and using objective, computational measurement tools hold promise over existing parent report and clinician rating scales, but even these new tools will likely be influenced by variables such as age, sex, gender socialization, socio-economic status, physical and mental health, and home and cultural environment.<sup>51</sup>

### Social communication and interaction

- 4.10 When assessing an individual's social communication and interaction, clinicians are required to identify deficits in social-emotional reciprocity; nonverbal communicative behaviours; and developing, maintaining, and understanding relationships.<sup>52</sup> Crucially, Autistic women and girls often present differently to Autistic males in relation to each of these three measures.
- 4.11 Compared to Autistic males, Autistic women and girls are more likely to be socially motivated,<sup>53</sup> to seek intimacy and companionship,<sup>54</sup> to display higher levels of social reciprocity,<sup>55</sup> and social and emotional insight,<sup>56</sup> and to pay more attention to faces and social images.<sup>57</sup> Autistic women and girls also use more social words, including during diagnostic assessments.<sup>58</sup> Notably, this is the case even where Autistic women and girls have equivalent social skills and challenges to Autistic boys.<sup>59</sup> As Cola et al. (2022) have written:

It is important to note that the expert clinicians in our study detected social communication challenges in autistic girls despite elevated levels of social talk, suggesting recognition that using social words is not the same as demonstrating social skills or possessing social understanding. More concerning is the possibility that other adults who are not autism experts (e.g., teachers, primary care physicians, parents/caregivers) may observe increased social talk in autistic girls—compared to autistic boys—and interpret it as an indication of increased social competence, thus reducing the likelihood that girls are referred for an autism evaluation in the first place.<sup>60</sup>

4.12 Autistic women and girls also tend to communicate (both verbally and nonverbally) in ways that are different to their male counterparts. This includes by using physical gestures in ways that are more noticeable and vivid and involve increased energy.<sup>61</sup>This finding is important for two reasons:

First, children with autism show deficits in the development of gestural communication; they gesture less and at lower rates compared to both typically developing children and also other children who are developmentally delayed. Second, gestures are coded under the communication section of ADOS-2 algorithm. The better an individual performs on gesturing, the lower the autism score he or she receives under this item on the algorithm.<sup>62</sup>

- 4.13 Patterns of speech and the use of linguistic markers may also have gender differences. While the use of linguistic markers, such as "um" and "uh", has been reported as low in Autistic populations,<sup>63</sup> recent studies indicate that Autistic girls, as well as neurotypical children, may use these markers differently to Autistic boys.<sup>64</sup> Speech patterns that replicate those of non-Autistic children may complicate the detection of Autism in women and girls, because they are a measure by which an individual's conversational and social competency is gauged.<sup>65</sup>
- 4.14 Further, and as noted above, assessments of social communication and interaction are inherently informed by social norms and expectations, including those related to gender.

### **Restricted and repetitive behaviours**

4.15 Restricted and repetitive behaviours refer to the expression of repetitive body movements or mannerisms, fixations or heightened interests in certain objects or topics, sensory behaviours, and routines and rituals.<sup>66</sup> Colloquially, these are often referred to as "stimming" (self-stimulatory behaviours to express or regulate oneself), Special Interests, sensory seeking and sensory avoidance, and an insistence on sameness.<sup>67</sup> There is some evidence to suggest that when undergoing diagnostic assessment, greater weight is attributed to restricted and repetitive behaviours in males than in females.<sup>68</sup> Some studies have argued that Autistic females are less likely to demonstrate restricted interests, which may pose a barrier to obtaining a diagnosis.<sup>69</sup>

- 4.16 However, it is not clear whether Autistic women and girls tend to score lower than males on measures of restricted and repetitive behaviours due to low levels of these traits, or because assessment tools are not sensitive to gender differences in how these traits might present. Notably, a study of Autistic children found that before the age of five, girls and boys demonstrated equivalent rates of restricted and repetitive behaviours, with differences emerging with development.<sup>70</sup>
- 4.17 While some studies indicate that masking and camouflaging behaviours influence the extent to which restricted and repetitive behaviours are identified during assessment, others suggest that behaviours and interests of Autistic women and girls may be more likely to be perceived as "typical".<sup>71</sup> Autistic women and girls may develop specialised interests in topics that are consistent with the interests of non-Autistic girls. There is also evidence to suggest that Autistic women and girls are less likely than Autistic males to have specialised interests involving objects.<sup>72</sup> Anecdotally, many Autistic women and girls report specialised interests in social or interpersonal topics, such as psychology, drama, or social justice. One Participant described:

Acting was my special interest. Almost every Autistic woman I know took acting classes at some point. Autism and acting feel very connected. It was a pathway to self-expression, where all of my big emotions were accepted. One of the first things I did after my diagnosis was write and perform a monologue about Autism. But acting was also a way to learn about human behaviour. I think my Autism was so masked because I learned how to perform in every aspect of my life.<sup>73</sup>

4.18 Participants also highlighted that specialised interests did not draw attention where they aligned with social and cultural norms:

I think my special interests went unnoticed because they were either considered "feminine" or "productive". When I spoke about my special interest in a celebrity, I was just a "fangirl". When I spoke about my special interest in my field of work and study, I was just "driven". When people use a deficit model for Autism, they only see the traits that they consider inconvenient, unproductive or disruptive to the status quo.<sup>74</sup>

4.19 Ultimately, if restricted interests and repetitive behaviours are used as critical diagnostic criteria, without attention to gender differences, Autistic women and girls may be missed.<sup>75</sup>

### **Diagnostic tools**

4.20 It is now widely acknowledged that the diagnostic and screening tools developed to diagnose Autism (including those considered the "gold standard", such as the Autism Diagnostic Observation Schedule) are largely based on the typical presentation of Autistic males,<sup>76</sup> and require observations of external behaviours.<sup>77</sup>

They therefore lack the specificity and sensitivity required to accurately identify Autistic females' traits and experiences.

- 4.21 It is also recognised that women and girls who exhibit similar levels of Autistic traits to males are less likely to receive a diagnosis when accessing clinical diagnostic services.<sup>78</sup> Similarly, a recent study indicated that Autistic women and girls experience greater discrepancies between clinician-rated and self-rated Autistic traits when undergoing assessment, with Autistic women and girls assessed as "less impaired".<sup>79</sup> These findings, alongside anecdotal evidence, indicate that diagnostic tools may be poorly suited to evaluating Autism in women, girls and non-binary people.
- 4.22 Participants also reported that the diagnostic tools can be difficult to interpret, particularly when Autistic traits are internalised. Given the higher prevalence of internalisation among Autistic women and girls, issues of misinterpretation may disproportionately impact this demographic:

When I've developed all these little strategies, I don't realise that other people can just get up and do the thing. And I have a 10 step programme for doing the thing which takes me all day. But the question is "can you do it?" Yeah. Yeah, I can do it. And there's no little box where you can explain, "yes, I can do it but only if this happened, or only in this scenario". There's no opportunity to explain. It's all just: you click the box and it assigns a number. Based off the box you clicked, you get a summary at the end of the numbers and then it's whether the number's high enough... there's no personalisation there. 80

4.23 A number of Participants recalled interpreting assessment questions literally, a known difference in Autistic language use and understanding:

I had to learn that if the question was "do you struggle with X?" and my answer was "no because I have a complex system for managing X", then yes, I struggle with X. It's like, "Do I struggle to make eye contact? No, it's uncomfortable, but I have this system where I count how many seconds I hold eye contact for, and then I look away at an object that I think your average person would look at, and count for a few seconds. And then I look back. But I can physically make eye contact, so I'll tick no.<sup>81</sup>

4.24 Participants therefore emphasised the importance of holistic and comprehensive assessment processes, which consider different sources of information and feedback, and allow for opportunities to reflect on assessment questions.

### **Developing gender-sensitive diagnostic tools**

- 4.25 In order to remedy gender bias in the diagnostic process, clinicians should seek to obtain an in-depth understanding of a person's behaviours and experiences across a variety of contexts, rather than relying on whether or not a person has met relevant score thresholds.<sup>82</sup> This requires a shift from male-normed diagnostic tools and a consideration of qualitative data.<sup>83</sup> Indeed, studies have demonstrated that expert clinicians achieve greater inter-rater reliability on diagnosis of Autism when using their clinical expertise rather than standardised checklists.<sup>84</sup>
- 4.26 Information should also be sought from multiple sources.<sup>85</sup> As one Participant described:

The psychologist who assessed me asked me to complete preassessment forms, which were open-ended. They interviewed my partner, and sought information from my family, and used different assessment tools. It took about 6 weeks and in that time, my understanding of Autism changed. I came to understand what the diagnostic criteria actually looked like in person. I remember taking one of the free screening tools before I sought assessment, and then after my diagnosis. I scored above the threshold for Autism both times, but my score post-diagnosis was about 60 points higher. I think it's because I knew what the questions actually meant in practice.<sup>86</sup>

4.27 The use of multiple and specific diagnostic tools may also remedy the often "abstract" criteria for diagnosis, making it less susceptible to bias. As Napolitano et al. (2022) have identified, broad and abstract constructs such as "deficits in social communication" may contribute to the under-diagnosis of Autism in women and girls.<sup>87</sup> Alternatively:

...studies that use narrow constructs (e.g., peer relationship; social attention; interpersonal motor synchrony; peer engagement behaviours; play behaviours; difficulty engaging in back and forth conversations, use of atypical gaze, and specific types of anxiety symptoms) could be more useful to highlight specific differences.<sup>88</sup>

- 4.28 Autistic women and girls also tend to present more atypical sensory profiles than Autistic males, reporting significantly higher scores in relation to hyper-reactivity and hypo-reactivity to sensory input.<sup>89</sup> Including an assessment of sensory profile during the diagnostic process may result in better outcomes for women and girls seeking diagnosis.
- 4.29 Clinicians should also consider the extent to which Autistic traits may be "masked" or "camouflaged", including where such behaviour is unconscious. In recent years, expert clinicians have used the Camouflaging Autistic Traits Questionnaire (CAT-Q), a diagnostic tool developed from Autistic adults' lived experience. The tool assesses individuals' own perceptions of three subcategories of behaviours: "compensation" (strategies used to actively compensate for difficulties in social situations); "masking" (strategies used to hide Autistic characteristics); and

"assimilation" (strategies used to fit in with others in social situations).90

4.30 However, as Pearson and Rose (2021) have written:

To reflect on masking, people must be aware that they are doing it. That may make it difficult to measure both the conscious and unconscious aspects. Researchers might attempt to examine this by comparing the masking experiences of people who have received earlier diagnoses with those diagnosed more recently, as well as whether community involvement impacts on how people experience masking.<sup>91</sup>

#### 4.31 As one Participant told WWDA:

I didn't really believe things like [masking]; that it was a thing that we did, or that people did. I wanted to go and ask someone else, to understand. Someone who wasn't autistic. And when my OT explained it to me, she talked about how we sometimes take on the traits of others or we hide our true selves because we're trying to fit in all the time. And I really do that a lot.<sup>92</sup>

#### Another Participant recalled:

I've had a lot of therapy and learning since I got my diagnosis and I have learnt how much I actually mask and now I can kind of almost describe it.<sup>93</sup>

4.32 Clinicians should therefore seek to educate women and girls seeking assessment in order to facilitate reflection:

I didn't know what masking was until I heard about it online. There's this idea that diagnosis rates are increasing because social media has made neurodivergence popular. The reality is that I was always Autistic, but Autistic people on social media platforms gave me the words for my own experience.<sup>94</sup>

4.33 Some Participants also spoke about being identified as potentially Autistic by other Autistic people. Known colloquially as being "peer reviewed", this is a common experience within the Autistic community, highlighting the utility of involving Autistic people in the design of diagnostic tools:

...it's sort of come up in conversation, and then they've gone, "wait, I thought you were Autistic, I thought you knew this". And then through those conversations, I did a bit more of a deep dive into everything... and came to the conclusion myself that I was neurodivergent, and then sought out a diagnosis.<sup>95</sup>

### **Differences in presentation**

- 4.34 Prior to the age of four, Autistic children show limited differences in the presentation of core Autistic traits.<sup>96</sup> Differences in core traits arise or become more pronounced as Autistic individuals age, and social and cultural factors influence gender differences.<sup>97</sup> Autistic traits may also become more pronounced when the demands of an individual's environment (including social, functional, environmental and emotional demands) exceed their capacity.<sup>98</sup> A number of Participants who were diagnosed in adulthood reported seeking diagnosis when they felt unable to manage the demands of relationships, health, and work or study.
- 4.35 As outlined above, Autistic women and girls may present differently to Autistic males in all elements of the core diagnostic criteria. This includes in relation to social motivation, social and emotional insight, language, non-verbal communication, interests, and repetitive behaviours. However, the literature presents mixed views on the origin of these differences. While some theorise that biological sex differences cause differences in presentation, others propose that differences may be driven by social environment and gendered socialisation.<sup>99</sup> As one Autistic advocate has written:

Autistic women and girls don't experience different Autism, they experience different prejudice.<sup>100</sup>

- 4.36 Many studies on the sex or gender differences in Autistic people conflate the concepts of sex and gender,<sup>101</sup> which may contribute to an undue emphasis on biological difference between Autistic males and females. Regardless of the cause, differences in the presentation of Autistic women and girls requires the immediate attention of researchers, health professionals, educators and the broader community.
- 4.37 As gender or sex differences emerge, Autistic women and girls are less likely to demonstrate "externalising" behaviours or traits, such as hyperactivity or behaviour considered disruptive. Rather, Autistic women and girls tend to experience internalised traits and struggles, such as anxiety, depression, and disordered eating.<sup>102</sup>
- 4.38 Autistic women and girls also engage in "masking" behaviours at a greater frequency than their male counterparts.<sup>103</sup> As outlined above, masking refers to the strategies an Autistic person uses (whether consciously or unconsciously) to camouflage or compensate for their Autistic traits and experiences. Masking is defined as the "suppression of natural responses and adoption of alternatives across a range of domains including social interaction, sensory experience, cognition, movement, and behaviour".<sup>104</sup> Participants described being quick to assimilate to the social environment, and hypervigilant to social cues.
- 4.39 Autistic women and girls also exhibit differences in empathic response to Autistic males. The 'Empathy Quotient' is a self-report scale commonly used to assess an Autistic person's experience of empathy; however, it is largely focused on

cognitive empathy (the ability to cognitively understand another person's mental or emotional state).<sup>105</sup> On measures of cognitive empathy, Autistic individuals tend to score lower than their non-Autistic counterparts.<sup>106</sup> This reductive measure of empathy is likely to contribute to the damaging myth that Autistic people do not experience empathy, which also poses a barrier to diagnosis:

When my mum asked my teachers if I could be Autistic, they said that I was too empathetic.<sup>107</sup>

- 4.40 Rather, is likely that Autistic people experience empathy differently to their non-Autistic peers. Autistic individuals show no differences from non-Autistic people in relation to the levels of attention paid to others displaying distress,<sup>108</sup> but may be more likely to experience affective empathy (by experiencing emotional arousal when observing another person's emotional state). When observing another person's pain, Autistic girls may be more likely to engage in emotion-focused comforting, while Autistic boys may be more likely to engage problem-focused comforting.<sup>109</sup> These gender differences can be seen across both Autistic and non-Autistic children:<sup>110</sup> the pro-social empathic responses, and emotional-sharing,<sup>111</sup> of Autistic girls may be more consistent with those of non-Autistic girls, than Autistic boys.
- 4.41 Further, many Autistic women and girls report experiencing "hyper-empathy", although there is little evidence-based research on this experience. One recent study has indicated that when Autistic women and girls experience shared affect, they may demonstrate less differentiation between their own perspective and the perspective of the other.<sup>112</sup> Difficulty distinguishing between one's own emotions and the emotions of another person was also reported by Participants:

I might not always understand them cognitively, but I can feel others' emotions as though they're my own.<sup>113</sup>

4.42 The dissonance between social perception of an Autistic person's empathy, and the individual's actual experience, may be explained by the "double empathy problem".<sup>114</sup> This framework posits that differences in perspective and communication between Autistic and non-Autistic people results in bi-directional breakdowns in interpretation.<sup>115</sup> This is an important framework because it disrupts the notion that Autistic people's ways of communicating are inherently wrong. Instead, Autistic and non-Autistic people have distinct and valid modes of interaction, and relational difficulties arise in response to that mismatch.<sup>116</sup>

### **MASKING AND CAMOUFLAGING**



### 5. MASKING AND CAMOUFLAGING

- 5.1 Autistic women and girls report that they engage in masking behaviours at a greater frequency and duration than Autistic males.<sup>117</sup> However, there is no sex or gender difference in reporting whether or not an individual "masks". <sup>118</sup> The heightened frequency in masking behaviours among women and girls may be due to increased rates of social motivation and other environmental factors.
- 5.2 As outlined above, masking may be both conscious and unconscious. While some researchers describe masking as a conscious social strategy to "fit in", others posit that it is a sub-conscious response to threat or trauma,<sup>119</sup> and an adaptive mechanism.<sup>120</sup> Ultimately, masking is "an unsurprising response to the deficit narrative and accompanying stigma that has developed around Autism".<sup>121</sup>
- 5.3 Common masking behaviours include developing scripts to navigate social interactions, consciously forcing eye contact, or internalising responses to sensory stimuli, such as fear or pain. One Participant described:

Before I was diagnosed, I didn't realise that I was masking. I knew that I had this internal script that had stage directions, and I knew that I put a lot of effort into my social interactions. But I didn't realise that other people didn't do that.<sup>122</sup>

#### 5.4 Another Participant explained:

When I go to work, I sit in the car and I take a deep breath and then I move out of the body of [me] the mum, [me] the person into [me] the... worker, and that means like, I feel like I become this different person... I feel like I contain myself in this different body all day. And then I be someone else and I use someone else's words and I do that so that I can keep my job and I can fit in and I can do what I need to do... And I don't even know who I am properly yet without the mask anyway. Because I don't always know how to take it off.<sup>123</sup>

5.5 There is some evidence to suggest that masking is linked to physical or psychological safety, a factor which may influence the higher rates of masking seen amongst women and girls, People of Colour, and people in the LGBTQIA+ community, who are already at disproportionate risk of harm, discrimination, abuse and violence. One Participant explained:

After I disclosed my diagnosis I almost felt pressure to unmask. I don't think people realise that it's something you learn throughout your

whole life, every time you get negative feedback. And unmasking isn't always safe. The people who had criticised me for having a blank facial expression before my diagnosis, were the same people who told me I didn't need to mask anymore.<sup>124</sup>

5.6 Indeed, many Autistic people experience marginalisation on multiple intersecting axis:<sup>125</sup> for example, Autistic people are more likely to be members of the LGBTQIA+ community.<sup>126</sup> One Participant told WWDA that masking their Autism can be a method of compensating for other ways in which they are visibly different:

I'm already aware of the way I present [as a gender diverse person]. I can't change that at the drop of a hat, whereas I can mask my Autistic traits like that. Straight away, I can reel that in and be slightly more acceptable to society... I'm aware that when I go out, I'm someone who visibly, people could make the assumption that that's a gender diverse person. That's already a lot. And then if I choose to unmask and have these visible Autistic traits, it's a very vulnerable position to be in and I'm potentially putting myself at risk...

Basically, I think I have to make that decision of: is it safe for me to maybe look a little bit more visibly autistic? Is that going to cause a disadvantage to me in that situation?<sup>127</sup>

#### 5.7 Another gender diverse Participant described:

I think for me being non-binary and queer, there's so much hiding, so much masking. Like there's so many things that all those different parts of me have to hide, to get through the day safely, to keep my job, or to not get hassled by people. So I feel like I don't really always get to be me.<sup>128</sup>

5.8 Assumptions about capability are also a barrier to "unmasking" (or openly presenting one's Autistic traits). One Participant described a concern that unmasking in the workplace would result in their employer making assumptions and decisions about their abilities, rather than consulting with them to understand their strengths and support needs. Other Participants had experienced this response, and other discriminatory practices, after unmasking or disclosing their diagnosis:

...when they didn't know that I was autistic, and when I was hiding a lot of the things about me, I was on a really good career path... And then when I felt like I was in a safe working environment, and I had safe people around me and I started to talk about being autistic... It was like this whole set of thinking shifted to, from me being this really capable amazing and talented human being that was set to do really well, to being this woman who needed to be babied, or who, you know, all of a sudden couldn't do things that she'd been doing for a really long time or, or couldn't handle the responsibility of that new project or couldn't, you know, possibly manage the team and do the work... it was almost overnight and so I ended up ultimately leaving because I couldn't handle it anymore. And it's disgusting, but also I couldn't make it a discrimination case because I couldn't prove anything. You know, I had no hard evidence, it was just subtle changes in behaviour that all added up to what it was.... And then when I went to a new job... I went back to hiding because I didn't want to see that happen again.<sup>129</sup>

#### 5.9 Another Participant recalled:

Within the week of informing my manager of the fact I'd received the diagnosis, I was required to undergo weekly supervisions, and could no longer manage my budget without clearing it through my line manager. Something I had been doing for more than 18 months. I was also immediately excluded from Board meetings and all planning and upskilling for the future [promotion] ceased. The only change that had happened was me informing them of my diagnosis. Eventually I left, and when I secured a new role I did not disclose my diagnosis, instead opting to return to masking my true self to keep my career. This absolutely destroyed my mental health in the end and I had to quit, taking time away from work to recover. So these days I mask heavily until I know the situation and who I can trust in the room, even when working in the disability sector.<sup>130</sup>

5.10 In reflecting on their experience in the workplace, one Participant also described the labour of representing multiple points of diversity as a gender diverse Autistic person:

I don't want to be the person carrying all of those vulnerabilities into my workplace. That takes so much... I don't have the capacity to be that person for everything, because then I'd be so drained after every day at work. Being the person who's, like, educating on every little thing in society that is not the typical presentation.<sup>131</sup>

### Impacts of masking

- 5.11 A number of studies have highlighted the adverse impact of masking upon Autistic individuals, linking masking with poor mental health outcomes,<sup>132</sup> and increased risk of suicide.<sup>133</sup> A 2018 study measured rates of suicidality amongst Autistic individuals compared with the general population, finding that masking behaviours significantly predicted suicidality in the Autistic group.<sup>134</sup> Importantly, masking or camouflaging was considered a unique risk factor for suicidality, independent of mental health conditions such as depression or anxiety.<sup>135</sup>
- 5.12 Masking may also be a risk factor for Autistic burnout, discussed in greater detail below.<sup>136</sup>

5.13 Loss of identity and low self-esteem are also common experiences amongst high masking Autistic individuals.<sup>137</sup> Such individuals report feeling that they do not know who they really are, and that their relationships with others may be built upon their masked selves, rather than their authentic selves.<sup>138</sup> This can increase feelings of isolation or being misunderstood.

# MISDIAGNOSIS AND UNDER-DIAGNOSIS



# 6. MISDIAGNOSIS AND UNDER-DIAGNOSIS

6.1 Due to misconceptions about the prevalence of Autism in women and girls, and its diverse presentations, many Autistic women, girls and non-binary people experience misdiagnosis or missed diagnosis. A recent qualitative study of Autistic women, girls and their families found that key roadblocks to earlier diagnosis included: age of pre-diagnosis indicators, mental health diagnoses, narrow understandings of Autism based on male stereotypes, and unavailable and unaffordable diagnostic services.<sup>139</sup> As Hamdani et al. (2023) have written:

For the most part, autistic characteristics of girls and women from this study were unnoticed or unremarkable until later along their developmental and social role trajectories between childhood and adulthood. Autism was less likely to be considered along the clinical pathway as the girls and women got older and not until a significant event or challenge related to daily life functioning was experienced. Recognition and diagnosis of autism occurred when demands for social interaction, academic, or professional performance increased, often at points of life stage transitions (e.g. elementary school to high school, post-secondary school to work).<sup>140</sup>

6.2 Autistic women and girls are more likely to receive diagnoses of depressive, anxiety, or personality disorders instead of, or prior to, an Autism diagnosis.<sup>141</sup> One Participant told WWDA:

> I saw seven different psychologists over 14 years before I was diagnosed with Autism. I remember psychologists pointing out all of these traits that they observed that I now know are Autistic traits. But no one ever mentioned the word Autism. At one point I was diagnosed with Adjustment Disorder, which makes me laugh now because of course I had difficulty adjusting to change: I'm Autistic.<sup>142</sup>

6.3 Multiple Participants had been incorrectly diagnosed with Borderline Personality Disorder prior to their Autism diagnosis. One described having their diagnosis revoked by a psychologist specialising in Autism:

> I had sought out this diagnosis because I was really struggling with my mental health... I was like, "well, everything I'm feeling matches Borderline Personality Disorder... So I got on a wait list... And it took almost a year for me to actually get an appointment there, and in that

space of in the space of that year, I had stopped being so majorly affected by these symptoms... I spoke to Registrar for an hour and did some questionnaires. And I got diagnosed with really mild BPD... And then it wasn't until I had my comprehensive neurodivergence assessment this year, which was like "you definitely don't have BPD". <sup>143</sup>

6.4 Many Participants spoke about misdiagnosis leading to inappropriate supports, services and "treatments", as discussed further below.

### **IMPACTS OF LATE DIAGNOSIS**



## 7. IMPACTS OF LATE DIAGNOSIS

7.1 Late diagnosis has significant impacts upon the life outcomes and quality of life of Autistic women, girls and non-binary people.<sup>144</sup> This includes in relation to health, access to support, education and employment. One Participant described how receiving her Autism diagnosis in her 60s had caused her to reflect on her experiences of schooling, exclusion, and relationships:

It just made my life so hard, not knowing. I think my life would have been really different, if someone had been able to help me understand that this is part of who I am.<sup>145</sup>

- 7.2 Another Participant explained that being undiagnosed and without support had had "an irreparable toll" on their nervous system, resulting in chronic physical health issues. Others described leaving workplaces, or becoming either underemployed or unemployed.
- 7.3 Late or missed diagnosis can also have a significant impact on the education outcomes of Autistic people, who are 50% less likely to obtain a Bachelor's Degree than other students with disability.<sup>146</sup> One Participant noted that had they been diagnosed earlier and received adequate support, they would have continued with their university studies. Instead, they explained:

I dropped out of uni because I experienced Autistic burnout and I just didn't know what was going on with my head and my body... I didn't have the words to explain what I was feeling... If I'd have known that I was Autistic and that I was experiencing Autistic burnout, and had support in place, I don't think that I would have dropped out.<sup>147</sup>

- 7.4 Notably, Autistic women and girls may experience disadvantage in the education system or in the course of employment even with a diagnosis. Many girls who are diagnosed with Autism do not meet the criteria for school-based funding, because they exhibit lower levels of disruptive behaviour and may have developmentally appropriate language skills.<sup>148</sup> As outlined above, this is not necessarily commensurate with having less challenges.
- 7.5 Participants also reflected on "Autistic burnout", a phenomenon only recently the subject of evidence-based research.<sup>149</sup> In one of the first studies published on Autistic burnout, it was defined as the "experience of a long-lasting pervasive state of exhaustion, loss of function, and reduced tolerance to stimulus that is conceptualized as resulting from chronic life stress and a mismatch of expectations and abilities without adequate supports".<sup>150</sup> In a thematic analysis of interviews with Autistic people, Autistic burnout was said to occur due to life stressors and barriers to support that ultimately outweighed abilities, resulting in negative impacts on

health, capacity for independent living, and quality of life.<sup>151</sup>

7.6 Masking or camouflaging, stigma, and discrimination are also key risk factors.<sup>152</sup> One Participant described:

It's like putting on some someone else's skin all the time. And that's really hard. And then sometimes I do it so much that I forget to not do it.... I reckon that's when I get burned out. Because I'm like, I'm like holding on so tight.<sup>153</sup>

- 7.7 Consistent with the existing literature, Participants reported that Autistic burnout was not well understood.
- 7.8 As one Participant explained:

The first time I experienced Autistic burnout would be from high school... I was very, very highly masked because I was desperate to fit in... I was putting so much energy into the social side of school and also so much energy into the academic side of school. And at the same time was in an abusive relationship and had really bad anorexia.... I just had nothing else to give, 'cause I'd given so much for so many years. And I put so much effort into everything, and I'd been so hypervigilant and like in such a state of "trying" for so long that I think my body, my brain, just gave out.<sup>154</sup>

#### 7.9 Another Participant described burnout being the catalyst for seeking diagnosis:

I'd had fatigue, chronic pain and frequent sickness for years. But when I started working full time in an office, it all caught up with me. I changed jobs, because I thought it was occupational burnout, but it didn't get better in my new job. I had constant brain fog and would have to take naps on my lunch breaks. I was always on the verge of panic or tears and I could barely cook or clean. The loud noises that I'd always hated sent me into panic. I got blood tests, and saw doctors, and thought it must be physical. And then a family member called me one day and said "I think you might be Autistic".<sup>155</sup>

### 7.10 Participants also described feeling a loss of identity and skills after being diagnosed as an adult:

I learned how I should function in this world without learning about my challenges or support needs. When I was diagnosed, I didn't know how to "be" in a way that wasn't highly masked or driven by adrenaline, or the fear of failing to live up to neurotypical standards. We spend our whole lives working double time to avoid standing out or being "too much". So when all of that fell away, I didn't know what my needs or boundaries were, or how to do the things I used to be able to do. <sup>156</sup> 7.11 Another consequence of a missed or late diagnosis is a denial of the opportunity to experience a community of people with shared experience.<sup>157</sup> Many Autistic people describe feeling misunderstood and isolated prior to obtaining their diagnosis:

...we see [an Autism diagnosis] as a positive now. But how many of us are missing out on that? How many of us are still sitting at home? Like metaphorically beating ourselves up because we think we're useless or we think that we can't, or "why are we so weird?" or "why don't we fit in?" when it could be something as simple as the right diagnosis?<sup>158</sup>

- 7.12 Conversely, personal Autism acceptance and positive Autistic identity are associated with better mental health outcomes.<sup>159</sup> For many Autistic people who are diagnosed as adults, a diagnosis provides a sense of self-compassion, permission to be oneself, and a sense that being different is acceptable.<sup>160</sup> Others describe feeling a sense of belonging within the Autistic community, and in this in turn contributing to greater self-acceptance.<sup>161</sup>
- 7.13 On positive Autistic identity, one Participant described:

I have a lot more empathy and understanding for my present self and also my past self. And it also means I can advocate better for myself in in situations where it's necessary, like at work or with medical stuff, I can go... "I'm autistic, I have support needs, but I am also an independent person and I'm capable of making decisions"<sup>162</sup>.

#### 7.14 Another Participant explained:

I'm kind of getting better at understanding what [it] means to me... it's not that I'm hopeless or bad or a terrible person. It's that I'm autistic and that it takes a lot of work to do those things. And more than the average person would take.<sup>163</sup>

### 7.15 As Autistic woman and Autism advocate Chloe Hayden told The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability:

Initially, when I was diagnosed as autistic, it was absolutely terrifying because the only understanding that we had of Autism was that it was a deficit, that there was something wrong with your mind if you were autistic... Now, as a 25-year-old, being autistic is something I am immensely proud of. It is who I am wholeheartedly and in its entirety... A diagnosis is something that is so, so deeply important for not just a child but for anyone to be able to understand who they are. People think that a diagnosis is going to label someone, but we as human beings label people anyway, so having a diagnosis simply puts the label into something that is in my control and in my hands.<sup>164</sup>

## **CO-OCCURRING HEALTH CONDITIONS**



# 8. CO-OCCURRING HEALTH CONDITIONS

8.1 Autistic women, girls and non-binary people experience various co-occurring health conditions which can have a significant impact on wellbeing. Studies on the prevalence and impact of these conditions on Autistic women and girls is limited. However, the available research indicates that Autistic women and girls may experience a higher prevalence of both physical and mental health conditions.<sup>165</sup> Further, Autism may impact the interactions women and girls have with medical, allied health, and service providers.

### **Mental health**

- 8.2 Anxiety and depression are among the most common co-occurring conditions for Autistic women and girls. As outlined above, a diagnosis of anxiety and/or depression may also disguise Autism, leading to a missed Autism diagnosis. A number of studies have indicated that Autistic women and girls may experience higher levels of anxiety than Autistic males.<sup>166</sup> Research also indicates that Autistic women and girls are likely to have co-occurring Attention Deficit Hyperactivity Disorder (ADHD), which may present differently in women and girls. Atypical ADHD traits (such as internalised hyperactivity or emotional dysregulation) in women and girls may lead to underdiagnosis or missed diagnosis.<sup>167</sup> Anecdotally, the combined impact of Autism and ADHD may serve to disguise both diagnoses.
- 8.3 As previously discussed, Autistic people are also at an increased risk of suicidality:<sup>168</sup> research has consistently demonstrated that both Autistic traits and the masking of those traits, are important risk markers for suicidality.<sup>169</sup> As persistent efforts to mask and camouflage one's Autistic traits has been consistently linked to poor mental health outcomes, clinicians should be aware that mental health conditions co-occurring with Autism may be related, in part, to masking,<sup>170</sup> as well as social stigma and discrimination.

### **Eating disorders**

8.4 Autistic women and girls are also at an increased risk of disordered eating.<sup>171</sup> Approximately 70% of Autistic people experience eating related difficulties, which may be caused by eating disorders, sensory aversions, or motor difficulties.<sup>172</sup> Autistic people do not only experience restrictive patterns of disordered eating (such as anorexia nervosa and Avoidant/Restrictive Food Intake Disorder) but also experience bulimia nervosa and binge-eating disorder.<sup>173</sup> 8.5 One Participant explained that for her, disordered eating was not due to sensory sensitivities, but was related to masking and control. She described:

I experience some alexithymia, so there are times when I have very bodily responses to emotional experiences. I feel things quite intensely within my body when I'm distressed, and I think part of my disordered eating was seeking a bodily solution to a bodily problem. I experience something emotionally distressing and I feel it in my body. And so I would look for ways that my body could experience control. I think my disordered eating was also about wanting to belong and not having another visible identifier of being different.<sup>174</sup>

#### 8.6 Another Participant stated:

I think it was 100% a product of masking. I felt really out of control of my whole environment with School, socially and... the pursuit of having the body type that was the societal standard of beauty meant that people liked me more because I looked a certain way. And it was like "Oh, I've done this to myself and now... I'm getting that validation from people. People are inviting me to parties and they want to be my friend. So this is working and I'm being accepted by everyone".<sup>175</sup>

8.7 As outlined above, there is also greater prevalence of gender and sexual diversity within the Autistic community: neurodivergent people are up to 7 times more likely to identify as non-binary or gender diverse.<sup>176</sup> Like Autistic individuals, members of the LGBTQIA+ community are disproportionately affected by eating disorders. This is particularly so for trans and gender diverse individuals whose disordered eating may be influenced by gender dysphoria.<sup>177</sup> The intersection of these identities may present a cumulative risk for gender diverse Autistic people.

### **Physical health**

8.8 Autistic women and girls experience more overall physical health challenges than non-Autistic women and girls, and Autistic men and boys.<sup>178</sup> They are at greater risk of cardiovascular and respiratory conditions,<sup>179</sup> gastrointestinal symptoms and disorders,<sup>180</sup> and reproductive health concerns than the general population.<sup>181</sup> There is also evidence to suggest a link between Autism and Ehlers-Danlos syndrome, a connective tissue disorder which can be associated with chronic pain.<sup>182</sup> One Participant explained that her Autism diagnosis made sense of her complex medical history:

> I believed that I had a whole range of independent health conditions. I had a history of anxiety and "panic attacks", disordered eating, chronic pain, gastrointestinal issues, hypermobility, menstrual issues, and ear nose and throat issues. Coupled with my interests-driven

personality, preference for sameness and routine, and sensory sensitivities, I was so clearly Autistic on paper, but it was overlooked. Getting an Autism diagnosis made sense of my whole medical history. It made me feel less distressed about my physical conditions, because I understood them more.<sup>183</sup>

### 8.9 Another Participant explained that their neurodivergence diagnosis provided context for their Chronic Fatigue Syndrome:

When I was going through getting diagnosed with chronic fatigue, it was suggested that my nervous system was stuck in fight or flight mode... They were like "your body is not going into the rest cycle... it's not resting, it's not digesting"...I think that is likely actually linked to neurodivergence... They wanted me to do a fatigue program... all that stuff that I would have gone through probably would not have helped and potentially would have even made me feel worse.<sup>184</sup>

8.10 Participants also described having "lightbulb moments" when reflecting on how Autism had interacted with their health conditions:

I was diagnosed with a chronic pelvic pain condition and I saw multiple specialists per week for years. I remember the day my pain specialist listed my pain condition as "extreme". I tried every treatment I could access. It wasn't until I listened to a podcast that I learned about the connection between neurodivergence and pelvic pain. I remember sobbing while I listened, wondering why no one ever told me.<sup>185</sup>

## **ACCESS TO SERVICES**



## 9. ACCESS TO SERVICES

9.1 It is widely recognised that women, girls and non-binary people experience unique barriers to healthcare, due to gender based bias.<sup>186</sup> Access to and experience of services can be also be uniquely complicated for Autistic people, including due to incorrect assumptions about individuals' skills or needs.<sup>187</sup> A number of Participants told WWDA that due to the barriers they face in accessing services, they do not seek support unless "absolutely desperate".<sup>188</sup> One Participant described feeling anxious about how she might present in medical or allied health settings:

I'm always aware that the way I present might impact how I am treated. If I don't disclose my diagnosis and I mask, I risk not getting support. If I don't disclose my diagnosis but I don't mask, I risk being perceived as weird or suspicious. If I do disclose my diagnosis and "seem Autistic", I risk being discriminated against or patronised. If I do disclose my diagnosis and I mask, I risk people not believing me.<sup>189</sup>

9.2 One Participant reflected on feeling scared and misunderstood by doctors while in hospital:

I found it really hard. There's so much noise in hospital... I was on edge all the time. I was on edge because I didn't know what the outcome of my treatment was going to be. But I was also on edge because, you know, there's strange people that I don't know and I have to explain myself again and again and again and again. And then I had one doctor say to me "Are you even listening to me" because I wouldn't look him in the face. I will do anything not to go back to hospital... I need that doctor who understands me and what I'm doing and why I'm doing what I'm doing. Some of the things I do [are] because I'm autistic, not because I need medication...<sup>190</sup>

9.3 Another Participant recalled a traumatic and discriminatory experience after disclosing her diagnosis in hospital:

When I was having my last child, I disclosed to the medical staff that I was autistic and as soon as I did so the medical people started talking about involving other government agencies such as child protection and the department of communities. This never happened with my other two children...<sup>191</sup>

9.4 The relationship between masking and access to services and supports was a common theme among Participants. One explained:

I've got a support worker and I'm masking for my support worker... she just wants me to be like her and so I try to be like her and then she goes at lunchtime, and I just, collapse. I'm exhausted.<sup>192</sup>

#### 9.5 Another Participant told WWDA:

I've gone into medical appointments and I have been unmasked, so I'm not making eye contact or I might be stimming, and the person has actually treated me as if I am less of an autonomous person who can make decisions for myself... To the extent where my GP discharged me from care because... I think she just went: this is a neurodivergent, Autistic person who has support needs. I don't want to deal with this. I don't want you to be a patient of mine.... I had gone into that situation thinking well, this is a medical practitioner, this is a safe place for me to be more unmasked. And it was not.<sup>193</sup>

9.6 Whether or not someone has obtained a diagnosis may also impact their access to and experience of services. One Participant described being discharged from their general practitioner's care after disclosing their Autism diagnosis and diagnostic report:

She had read the quantitative report that was following the medical model, the deficit model. So she read all of that and went: "I don't want to deal with this person".<sup>194</sup>

9.7 Prior to diagnosis, one Participant recalled feeling that health professionals perceived her as "dramatic":

I feel extremely vulnerable in medical settings, which I think is a combination of medical trauma, sensory overload, and phobias. I've always felt that medical professionals perceive me as overly emotional or dramatic. They often ask "why are you crying?", or "why do you need your partner here?", or minimise my experience of pain. I remember getting an annual check up on my IUD. Even though I had a history of chronic pelvic pain and anxiety, the doctor couldn't understand why I was distressed about an internal pelvic exam. It wasn't until I told her that I was exploring diagnosis for Autism that she let my partner stay in the room.<sup>195</sup>

9.8 Participants also reflected on having to choose which one of their identities or diagnoses they would prioritise when seeking healthcare:

I've never really experienced a trans-affirming healthcare provider before... [they have] misgendered me, not understood, not really wanted to deal with it. And so I wouldn't seek out trans-affirming healthcare from them. My main priority is neuro-affirming, and can deal with the chronic illnesses, and most importantly, will [they] prescribe my medication.<sup>196</sup>

- 9.9 This is consistent with Australian research on Autistic people's access to healthcare, which identified that Autistic adults who are gender-diverse experience additional barriers.<sup>197</sup>
- 9.10 A missed or late diagnosis may also cause an individual to engage in therapies or support services that are not tailored to their unique needs as an Autistic person. Many Autistic adults report that they do not benefit from standard psychological therapies, such as Cognitive Behavioural Therapy.<sup>198</sup> Participants therefore reflected upon misdiagnosis as a barrier to appropriate therapeutic approaches:

I was just told that I have social anxiety... And I always... felt so much frustration. Because with social anxiety you're told, like with anxiety in general, it's like exposure therapy, right? You do it and it gets easier... It was like "I'm putting myself out here, I'm trying really hard. It's not going away and it isn't getting easier"... Now having received my diagnosis, I understand. It's never gonna get easier, but that's OK. And I feel like I have a lot more acceptance with it, as opposed to just feeling like there's something wrong with me and I'm not trying hard enough to fix it, because I'm told that it can be fixed.<sup>199</sup>

#### 9.11 Another Participant recalled:

Before my Autism diagnosis, I remember being so frightened by loud noises that a psychiatrist told me to smash plates, so that I could desensitise myself. Now I know that CBT and exposure therapy won't change the way my brain processes sensory input<sup>200</sup>

#### 9.12 A Participant who had received multiple misdiagnoses described:

My whole life they've told me this is who I am. And that's why I'm doing the things that I'm doing, and just medicate, medicate, medicate, and medicate. Try this. Try that. And did you know, I even had one doctor tell me I was a lost cause.<sup>201</sup>

- 9.13 Having regard to the significant health concerns that Autistic women, girls and non-binary people experience, their access to appropriate care, supports and services requires urgent attention.
- 9.14 Further, access to disability-specific support and funding, such as the National Disability Insurance Scheme (**NDIS**), is hindered by diagnostic gender bias. Across Australia, Autistic NDIS participants make up 35% of total participants, but 70% of those participants are male.<sup>202</sup> As outlined above, Autistic women and girls who obtain an Autism diagnosis are likely to exhibit greater impairment in everyday life than Autistic males. If Autistic men and boys make up the majority of Autistic NDIS participants, it is likely that there are many undiagnosed Australian women and girls experiencing significant challenges without government-funded support:

Basically, they said, "well, no, you're married, you've got a job, you're buying a home, the impact on you is not significant enough"... Just because I've got my mum and my dad and my sister and back then my husband who will pick up for me when I... fall over, which is get becoming more and more regular, doesn't mean I don't need help. It doesn't mean I'm not significantly impacted... I haven't reapplied, I don't know if I want to be put through that all again, because you know, getting all the evidence and stuff like that. So I actually don't have any form of support at the moment. And I don't know if I'll ever be ready to try again, because it's really traumatic. And to be told that was basically humiliating, and it's really impacted me a lot.<sup>203</sup>

9.15 Participants who did receive NDIS funding spoke about the positive impact it had had on their lives, including in relation to access to services, capacity building, and engaging in community:

I've got an NDIS plan now and I have support workers come. And I've started my own business... but if I'd had that a lot earlier, like I think about what my life would be like. It would be really different. And maybe I would have been able to get help much earlier to even have relationships with other people... I never even really had a birthday party until last year when I was 62, and that really only happened because I had help... Through my NDIS, I've met people and I learned about how to be around other people. We got together and I had a birthday party. 62! My first real big party!<sup>204</sup>

### 9.16 However, one Participant expressed a fear of having her funding removed and being left with nothing:

Especially as I get closer to 65, I'm really scared that they'll take that away from me and I'll just be left with nothing again... If they take this away from me, and they leave me with nothing, I don't want to be here anymore. My mom is in her 90s. She's gonna be gone soon. Who else? So take that away from me, who else is there? Who else is going to help me navigate things?<sup>205</sup>

#### 9.17 Another Participant echoed a feeling of insecurity as an NDIS Participant:

I'm worried that, because I don't present "stereotypically", someone might decide I'm not Autistic enough and remove the funding. I attended an NDIS meeting recently in support of someone else and I was scared that how I presented when I advocated for them would mean the NDIS would decide I wasn't disabled enough. Even the other day, I received a letter about my current plan and funding being continued for a further 12 months, and because it didn't explicitly say that my funding would be renewed, I was scared that they just meant I had to make my existing funds last for another year. Autistic people often interpret language literally, so it's important to be clear.<sup>206</sup> 9.18 Others expressed difficulty using their funding and accessing the right supports, and feeling overwhelmed by the process:

I'm still navigating the whole NDIS thing.... It's a lot of work actually to have an NDIS plan. And I don't think it should be that much work, but it is.<sup>207</sup>

9.19 One Participant also recalled a traumatic experience they had had with an NDIS funded support worker, and how difficult it had been to find a support worker they felt safe with:

It's tricky... finding a support worker who's going to understand that I'm not just autistic, that I am non-binary, and I am queer and that I'm allowed to be, that's who I am. I had this support worker come in last year, from this agency that I had started working with, and she kept misgendering me, like saying to me, "no, you can't be a 'they', you have to be 'she' or 'her''. Like "no, 'they', that that's my pronoun". She said "No, you gotta be 'she' or 'her'". And then when she found out that I was queer, like she wanted to pray over me all the time... There's nothing wrong with who I am. You know, that was really traumatic and it took me ages to let anybody else in through the front door.<sup>208</sup>

### **APPLIED BEHAVIOURAL ANALYSIS**



## **10. APPLIED BEHAVIOURAL ANALYSIS**

- 10.1 A final theme emerging from the research conducted is the potential for poor mental health outcomes associated with Applied Behavioural Analysis (ABA). ABA is one of the most prevalent early childhood interventions recommended by clinicians when children receive an Autism diagnosis.<sup>209</sup> Therapists seek to modify behaviour with the use of a rewards-based model, to promote behaviours that clinicians consider appropriate. While ABA is most prevalent in the United States, it has a continued presence in Australia.
- 10.2 In addition to being the most common early childhood intervention, it is also the intervention with the highest ratings of post-traumatic stress symptoms in both children and adults.<sup>210</sup> A 2017 study of Autistic adults and caregivers of Autistic children found that exposure to ABA predicted a higher rate of, and more severe, post-traumatic stress symptoms in participants.<sup>211</sup> Respondents who were exposed to ABA were 86% more likely to meet the criteria for Post-traumatic Stress Disorder (**PTSD**) than those who were not exposed to ABA.<sup>212</sup> For Autistic respondents, increased duration of exposure to ABA was associated with greater severity in post-traumatic stress symptoms.<sup>213</sup> Based on the findings of the study, the researchers predicted that nearly half of Autistic children exposed to ABA would be expected to meet the diagnostic criteria for PTSD just four weeks after commencing ABA.<sup>214</sup>
- 10.3 Although the utility and ethics of ABA are debated by clinicians and behaviour analysts, the voices of Autistic individuals must be paramount. WWDA strongly condemns any practices that deny people with disability self-determination and autonomy. Although practitioners no longer rely on punishment for behaviour modification, ABA was founded on the goal of making Autistic individuals "indistinguishable" from the non-Autistic population.<sup>215</sup> Whether this remains an implied or explicit goal of ABA, causing an Autistic person to suppress their natural tendencies in order to adapt to non-Autistic forms of interaction is cruel and damaging. It is also crucial to acknowledge the harmful historical origins of ABA, and its connections to LGBQTIA+ conversion therapy practices.<sup>216</sup> While LGBQTIA+ conversion practices have been broadly condemned in Australia, and outlawed in several states and territories, ABA continues to hold its status as a valid therapy. WWDA calls for the condemnation of Autistic conversion practices with the same rigour.

## **ENDNOTES**



### **11. ENDNOTES**

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### Women With Disabilities Australia (WWDA) has Special Consultative Status with the Economic and Social Council of the United Nations.

#### Awards

Winner National Human Rights Award 2001

Winner National Violence Prevention Award 1999

Winner Tasmanian Women's Safety Award 2008

Nominee UNESCO Prize for Digital Empowerment of Persons with Disabilities 2021

Nominee French Republic's Human Rights Prize 2003

Nominee UN Millennium Peace Prize for Women 2000

**Certificate of Merit** Australian Crime & Violence Prevention Awards 2008

Nominee National Disability Awards 2017

Finalist International Zero23 Award, Information and Communication Technologies (ICT)